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ABSTRACT

This report provides a record of discussion during a workshop entitled "Assisting People with Developmental Disabilities To Speak Effectively for Themselves." Participants included developmentally disabled individuals, leaders from self-advocacy groups, paid staff, and volunteers. The discussion addressed three questions: (1) what works to help people speak for themselves to change their lives? (2) what works to help people speak out to change conditions for all people with disabilities? and (3) what will strengthen self advocacy? Among the topics covered by discussion participants were: person-to- person support; empowerment; support from local self-advocacy chapters; supporting the development of local chapters; becoming politically active; defining positions; involving community leaders; coalitions; influencing the media; participating in disability service organizations; local and state chapters; national efforts; and next steps. (DB)

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Effective Self Advocacy

Empowering People with Disabilities to Speak for Themselves

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Research and Training Center on Community Living
Institute on Community Integration
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Effective Self Advocacy

Empowering People with Disabilities to Speak for Themselves

Report #90-4 • October 1990

Research and Training Center on Community Living
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The opinions expressed in this report do not necessarily reflect the position of NIDRR, the Research and Training Center on Community Living, the Center on Human Policy, or Responsive Systems Associates.

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Introduction

This report is a record of the discussion during the workshop, "Assisting People with Developmental Disabilities to Speak Effectively for Themselves", held at the 114th Annual Conference of the American Association on Mental Retardation, May 30, 1990. The workshop brought together 18 people from seven states who have extensive experience in developing self-advocacy groups for persons with developmental disabilities (the list of participants is on the following page). Some of the participants were people with developmental disabilities. Some were leaders from local and state self-advocacy groups. Some were paid staff responsible for supporting self-advocacy, and some were volunteer helpers for self-advocacy groups.

This report contains the comments made as participants shared their experiences in response to three questions:

1. **What works to help people speak for themselves to change their own lives?** (pages 1-5)

2. **What works to help people speak out to change conditions for all people with disabilities?** (pages 6-11)

3. **What will strengthen self advocacy?** (pages 12-14)

The discussion was recorded on large wall charts by workshop facilitator John O'Brien, who then put together this report from that record. Participants reviewed summaries of each part of the discussion for accuracy. The words and images are those of the participants. They have been edited and arranged to make them easier to read. Because the purpose of the discussion was to share ideas, not every participant necessarily agrees with every point and position in this report.

About words . . .

One sign of the healthy diversity in self advocacy is the wide variety of names groups use. To keep things straight, we'll use these general terms in this report:

member: a person who belongs to a group of people with disabilities working to empower one another to make changes in their own lives and to change conditions for all people with disabilities.

chapter: an organized self-advocacy group. Often local groups are part of a state organization.

representative: a self-advocacy group member who represents the group on a council, board, committee, or task force.

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1 What works to help people speak for themselves to change their own lives?

The daily expectation that people will speak for themselves.

Person-to-Person Support

❑ Speaking for yourself begins in day-to-day life. To learn to act as a responsible adult, other people (parents, relatives, friends, and staff people) have to see you and treat you as a responsible adult every day. A person's ability to speak for him or herself grows when others:

- Firmly believe that the person has the right to choices, both in everyday life and in setting life goals.
- Do not label the person, but get to know the person for him or herself.
- Ask and listen with care to what the person wants, what the person's goals are, what specific help the person needs.
- Focus on the person's capabilities, not the person's inabilities.
- Match supports to the person instead of fitting the person into what's available.
- Encourage the person to work on what the person wants, even if it is hard to see how far the person can go toward a goal.
- Work along with the person to find ways to make what the person wants possible by helping with problem solving and by connecting the person with other people who can be trusted to help.
- Realize that the person can learn from mistakes if the person has the right to make them and the support to figure out what went wrong and how to move on.
- Recognize that it's OK for the person to say, "I hate this. Let's start over!"

❑ This sounds simple. But it isn't the way day-to-day life has been for most members. For most members, labels mean that other people automatically think they know better.

- There is no expectation that people will speak for themselves in most of the residential and day services members rely on. Staff expect members to follow instructions, not to be in control of their daily lives. Staff routinely take over even simple things like when to get up and go to bed, what to wear, and what to eat.

Labeling, poverty, and fear of punishment hold people back.

- Many people's parents maintain control of their adult children's lives. These people may not even be allowed to join a self-advocacy group. Some members feel shut-up at home: they aren't allowed to go out except to programs where staff act like parents, and their parents don't want to hear about their choices.
- Many members were put in institutions, sometimes cut off from their families from a very young age. This means that many members have to work out ways to deal with a lot of pain. And it can make it hard for a member to know who to trust. It's hard to focus on a good future when you've had a hard past.
- Some members live in small residences that are very restrictive. For example, one person lives in a residence that doesn't allow visits from self-advocacy group members and limits the person's phone calls. Other members live in places where staff go through mail and "lose" notices of self-advocacy activities.
- Members often feel that other people don't want to hear what they think. Some have been punished for speaking out for themselves. Many members are afraid that if they speak up, they will lose the help they need.
- It's very rare that services get developed by asking the person what's needed. This means that lots of service mistakes are made. Staff don't usually want to hear about mistakes they have made from the people whose opinions they've ignored.
- In some places the people who are supposed to protect people's rights work for the same system that caused the problem. Sometimes people's concerns are referred and the people who are supposed to take action use confidentiality to avoid being accountable to the person. Sometimes people who are supposed to protect or advocate won't listen or take the time to get to know what a member really wants. Just because people are called advocates doesn't necessarily make them friends.
- Members are usually poor. The more a service costs, the less control people have of their money.

❑ As a result of all these experiences, fear holds most members back. They have been intimidated by fear of punishment or failure and told they can't do things so often that they lack confidence.

Empowerment

Empowerment

❑ The answer to fear and silence is empowerment. Empowerment equals personal and group connections plus information plus money. More and more professional people talk about empowerment: check to be sure that they mean building connections, sharing information, and giving people control of money. More and more people use the term, "self advocate," sometimes just as another label for someone with a disability. Real supporters of self advocacy know that a self advocate is a member of a group working to empower people with disabilities.

❑ The expectation of people making choices, with the help they need to carry them out, needs to begin very early in life. Families of babies with disabilities need to know that chances to choose have to be part of a person's life from the beginning. Families and growing children with disabilities need to know and learn from adults with disabilities.

❑ To really establish the expectation that people with disabilities should speak for themselves, we have to reach out into the community. People who have been segregated have to join neighborhood and workplace activities and invite community leaders to join in working on issues that make a difference to people with disabilities.

Support from Local Chapters

❑ It's a mistake to assume that people with disabilities don't need support to speak for themselves. People need help from one another and from advisors. It takes time to learn to know and trust one another. If members are to grow stronger, they need time to get involved. The rule is, go slow and do it right.

Leading in a danger zone

❑ Speaking for yourself happens in a danger zone. On one side is a service system that often fails to respond well to people and then labels and blames them for the problems that result. On the other side is people's private lives, which can be mixed up and difficult. If chapter leaders are going to help other members speak for themselves, they have to work in this danger zone. To do that effectively, they have to build trust. The chapter has to be like a good family for people. This means:

- Leaders work on taking care of their own lives, with help from other members.
- Leaders have a real concern for other members' health and well-being:

A safe place where people feel welcome and valued for themselves.

...They are people that members feel they can talk to safely.

...They take time to get to know people and spend social time with members.

...They seek members out when they are in down times by visiting members in the hospital, going to see people when a family member dies, or calling members who are depressed.

...They build people's confidence by helping them figure out what to do to work on a goal or a problem and complimenting members who do a good job.

- Leaders don't act superior.
- Members don't put other members down.
- Members take care of each other; they make it clear to every member, "We'll back you up. We won't hurt you."

...If someone gets hurt by the group or by another member, it's ok for the person to say so and other members will try to find a way to solve the problem.

...Members respect confidentiality. Things that are said in meetings stay in the meetings. Service provider staff are not present at meetings.

Speaking for Ourselves in Philadelphia has helped members make partnerships. Members are encouraged to match themselves with other members to share social activities or help each other out.

- Chapter meetings are run so people feel included:

...Make the agenda clear and notify people with phone calls and newsletters (be sure newsletters are on tape for people who have trouble reading).

...Meet in accessible community places.

...Keep working on transportation so everyone who wants to come can come.

...Have clear rules for the meetings so people feel safe (no fighting or put-downs), people feel like decisions are made fairly and after a chance for discussion, and people who don't understand have a chance to ask questions and get explanations.

Supporting the Development of Local Chapters

❑ We need to recognize the way strong local chapters develop.

- It takes time for a chapter to develop. If a group takes on responsibility for lobbying or other kinds of outside change activities too soon, there isn't time for members to develop leadership. Only a few people of the most able people act as spokespeople and others don't get a chance. Taking the time that it takes to

Go slowly and surely. Don't let outside expectations take over the chapter.

grow can be hard if outside groups, expecially funders, expect big results in six months or a year.

- Members should figure out and do things without extra money before they look for funding from outside groups.
- Once a group is ready to apply for grants, members have to learn about budgets, proposals, contracts, and deadlines.
- It's important not to let work on a project keep chapter leaders from taking the time to involve members in activities.
- Agencies that fund chapters - like developmental disabilities councils - should be sure that they have simple, clear instructions about what they want in proposals. It takes a lot of time to involve people in re-doing things that were hard to understand in the first place. It works well if there is a person from the funding agency who will answer questions and help. Otherwise, the grants just go to the people who know how to write them.

Helping Members Make the Most of Individual Program Planning

Most service systems now use IPPs (Individual Program Plans). Members need support to get the best possible outcome from IPP meetings. They need help matched to their individual requests, including:

✔ Someone to go along to the meeting to support them, especially if they are going to challenge what the service providers want to do.

✔ Information about how the process works.

✔ Information about who will be there.

✔ Information about what data will be used (some members have been to meetings where the service providers used inaccurate information from outdated institution files).

✔ Help to say exactly what they want.

✔ Ideas about what's possible and what kinds of services could be available, and help to define high expectations for themselves.

✔ Connections to people who can help if they don't agree with the decisions of the IPP team.

The IPP process can have problems:

...Sometimes people live in a bad place, but none of the professionals have a way to help a person move. This can make the IPP meeting hollow.

...Sometimes staff get upset when someone disagrees with them.

...Appeals can take a long time and still not result in changes.

2 What works to help people speak out to change conditions for all people with disabilities?

❑ Once people with developmental disabilities have the support to speak for themselves and work for choices in their own lives, they can work to change things for all people with disabilities by doing the following:

- Becoming politically active.
- Defining their own positions.
- Forming or joining coalitions for change.
- Involving community leaders in their lives and in their issues.
- Influencing the way the media presents people with disabilities.
- Participating in disability service system councils, boards, task forces, and committees.
- Reaching out into the community for help.

Becoming Politically Active

❑ The first step is to educate members in how to be active citizens.

- Members need information about what local, state, and federal governments do, how elections work, how to vote, how to get involved with a political party.
- Chapters need to make sure that local voting places are accessible and that people who have trouble reading have the help they need to vote.
- An annual legislative rally can help members learn how the legislature works while presenting issues to their legislators.
- Local meetings with legislators, before the legislative session begins or before elections, give members a better chance to educate their representatives.
- A written legislative program, agreed to by local and state members, gives a focus to local legislative meetings and other lobbying work.

Washington People First has a voter education handbook for its members. Local civic groups, like the League of Women Voters, can teach members how to vote.

- Knowing legislators' voting records on issues that matter to members makes it possible to find out why a legislator agrees or disagrees with members (in some states, a state disabilities advocacy group or coalition tracks legislators' votes).

❑ Public actions are sometimes necessary.

Defining Our Own Positions

Washington People First has developed statements about, "What we want..." from different services. Last year the state board reviewed proposed state service guidelines to make sure that they matched People First's position.

❑ There is power in numbers. When a number of members work together to decide what is important to them, the ideas are better than if just a few people think things up. And, it's powerful to be able to say, "*Our members have worked on this and they agree that this is what they want.*" Once a group has agreed on a statement, then:

- Members can present it to elected officials, news people, and service provider groups.
- Members can check proposals - like new laws or regulations, or other groups' proposals - to see if they include things that are important to the chapter.
- Representatives on boards or committees can use the statement to help them figure out how they stand on issues that come up.
- As members talk to other people about the chapter's position, they will get new ideas that they can bring back to the group to make their position stronger.

Involving Community Leaders

❑ We need to open our doors to the community, not just fall back on the same supports (service providers and disability advocacy groups). If we push ourselves to reach out and ask specifically for the help we need to take action, some people will help. And getting involved personally is the best form of education.

Nebraska Advocacy Services has helped Nancy Ward, its state self-advocacy staff person, to recruit mentors skilled in community organizing, finance, and office management.

❑ Community leaders can serve as mentors for chapter leaders. Mentors help people learn by sharing skills and advice.

Coalitions

Self Advocates of Central New York has joined a coalition to close the local institution.

❑ A coalition brings different groups of people together to work for change on an issue they each believe is important.

❑ Working in coalition gives a chapter more power.

❑ Coalitions give members a chance to develop leadership skills. Co-leading a coalition with a person from another group can give people good experience.

❑ It's important to look carefully at the pluses and minuses of joining a coalition:

- Members can be uncomfortable working outside their own group.
- If members in a coalition sit back, people from other groups may take over. This can lead to hard feelings.
- Partners in a coalition may not have positive attitudes toward people with disabilities. They may not know how to listen or how to work with people with disabilities as equals.

Some issues for coalitions with senior citizens and other disability groups:

- Accessability
- Attendant care
- Getting people out of nursing homes and institutions
- Waiting lists

Influencing the Media

❑ The way television, radio, and newspapers show and talk about people with disabilities makes a difference for good or for bad.

❑ Watch the way people with disabilities are shown. Chapters should reward positive stories that stress that people with disabilities are people first. Chapters should protest negative stories that feed into labeling.

To help with influencing the media, get the publication, *Reporting on Disability: Approaches and Issues*, from Advocate Press, 1974A Douglas Blvd., Louisville, KY 40205.

❑ State and local chapters need to work on getting media coverage of issues as well as people. Human interest stories are great, but we also need good coverage of the political issues that make a difference to people with disabilities.

Participating in Disability Service Organizations

❑ More and more disability service providers and disability advocacy organizations are asking members to serve on councils, boards, task forces, advisory groups, and committees. Members' involvement in disability service organizations can make a positive difference for people with disabilities and can help the members involved develop their leadership skills. But when an organization only wants token disabled people or fails to organize its board and committee

work for success, joining can be a frustrating waste of energy. To decide whether to join, find out if the organization can help, and if the organization is set up for success in including members.

Can the organization help people with disabilities?

❑ The first thing to find out is what the whole organization does. Be able to say how the organization's work will help members get more of what's really important for them. If the organization does things that are opposite to what members want, such as controlling people's choices or running restrictive group homes, do they want to change?

❑ Then find out what the board or committee or task force does. Sometimes boards or committees really make things happen; sometimes they are just a rubber stamp:

- What decisions does it make?
- If a committee or task force is giving advice, who decides about what happens to the advice?

Is the board or committee set up for success?

❑ Are there places on the board or committee for at least two members? This helps because:

- A more experienced person can go with a less experienced person, which builds leadership.
- If one person can't come, the other can represent the chapter members and keep the absent person up to date.
- Even very experienced members feel more confident when they attend meetings with someone they know.

❑ Avoid big words and jargon. Write things clearly, in understandable language.

❑ Put things on tape and communicate with pictures and through personal briefings for people who have trouble reading.

❑ When the board or committee deals with complicated issues, it helps to have a person to be a facilitator. The facilitator's job is to help the representative understand what is going on by reading and explaining written materials, to help the representative decide what he or she wants to say, and to assist the person in getting to and participating in the meeting. The facilitator only provides the specific help the person needs. The facilitator supports the representative to say what he or she thinks, not to say what the facilitator thinks.

The Washington DD Council pays People First to facilitate People First members' participation.

❑ Organizations with budgets should invest money in supporting the participations of people with disabilities by paying to:

- Support facilitators.
- Be sure representatives don't lose money.
- Make adaptations to make it easier for representatives to participate.
- Provide financial support to the chapter so representatives will have a strong foundation.

What works for people with disabilities, works for everyone.

❑ Any group works better for everyone when:

- There are clear ways to discuss things and everyone knows how decisions are made versus getting bogged down in group politics.
- Meetings are not too formal.
- Staff help the group do its job instead of taking over or pushing their own ideas no matter what the board thinks.
- Time is taken to develop personal relationships so people don't feel intimidated, like "They are up there and I'm down here."
- People listen to one another with respect, with no put-downs and valuing what each person says.
- People can ask questions to clarify what they don't understand.
- Small groups are assigned to talk things over and get things done so people can really discuss things and influence each other.

Members learn most from the way their chapter works.

❑ The chapter is important to members' successes in other organizations:

- The way the chapter's board and its meetings work teaches members how to participate in meetings and how to be better problem solvers.
- Training for officers and members builds skills.
- Retreats help representatives get clear about what they believe.
- Members with more experience on boards can be coaches for new representatives.
- Better ideas and more strength come from making time in chapter meetings for representatives to report on what happens on other boards and committees and to ask members for input.

- Special meetings to compare laws, regulations or plans with the chapter's desires helps representatives give better opinions.

Advice for Members Joining Committees and Boards

✔ Be sure you know what the expectations are:

- How often are meetings held?
- How long are they?
- Where are they held?
- Do members have to pay for anything, and, if the organization pays people back for expenses, what is covered and how long does it take to get paid back?

✔ Listen carefully and wait until you pick up what's happening in the meeting before you speak.

✔ Find out what you don't know before you speak.

✔ Practice being concise and clear when you speak.

✔ If you don't understand something, ask questions. If you still don't understand, ask more questions.

✔ Take the time to decide what you think about issues the board or committee is deciding about. Talk to other members and advisors. Write down what you think.

✔ Report back to the chapter and ask for ideas.

3 What will strengthen self advocacy?

Local and State Chapters

Keep up people's energy for the long haul.

❑ We expect a lot of our members and our helpers. They have to go to many places and do many things. Some actions lead to change, but some don't. We are working on big issues that will take us a long time to change. We get tired and have to think about how to keep from burning out.

- Active people have to remember that no one person has the answer.
- We have to involve other people in the chapter's work. Some kinds of work, like mailing, can be done at parties.
- We need to develop other members as leaders.
- If we agree to work on projects and grants, we need to build in time enough to do them so we can take personal time sometimes and not wear ourselves out.

Think about ties to ARCs.

❑ We have to think carefully about our relationship with service providers and ARCs (Association for Retarded Citizens: "They have to change the name!").

- There are many issues around which chapters might join ARCs and service providers in coalitions.
- Even though lots of ARCs want to sponsor chapters, there are dangers in becoming too closely identified with ARCs:

  ...Many ARCs are service providers and have discouraged members from speaking for themselves when it would embarrass them.

  ...Many ARC leaders still believe that "parents always know best" and aren't ready to work to overcome that history.

  ...Many chapters affiliated with ARCs are little more than segregated recreation programs rather than active workers for empowerment even though the members are called "self advocates".

  ...Identification with ARC narrows a chapter's focus to people with mental retardation, although many chapters include people with other developmental disabilities.

Nationally

❑ People from around the country need to meet regularly to share and plan together.

❑ We know better than ever what we want: homes, a choice of jobs, personal assistance, and people out of institutions and nursing homes. But we need to learn a whole lot more about how to do it in a way that builds in the expectation of self advocacy.

❑ Some of what members need depends partly on what the federal government does. We need to be active to make sure that changes in laws and changes in funding (like Medicaid) increase members' choices and power. We need a way to figure out a national position on common issues.

It's time for a national resource, controlled by self-advocacy groups.

❑ National groups, like AAMR ("What an awful name!") are thinking about having people with disabilities on their boards ("How about having half the board be people with disabilities?"). We need to think about how to be sure that any representatives have the support of chapters from all over the country.

❑ More and more groups are forming. New groups need resources and assistance so that they grow strong and increase members' empowerment. If help from strong chapters isn't available, new groups can turn into segregated recreation programs or can get so busy meeting outside expectations that they don't take the time to grow strong. We have to be careful; lots of people already use the term "self advocate" as just another label for a person with mental retardation instead of as a description for a person who is a member of a group working to empower its members to increase connections, information, and control over money.

❑ Laws are changing (like the Americans with Disabilities Act). Chapters need understandable information about what all this means.

❑ We need a national "thing" to help with development. We call it a "thing" because we don't know yet exactly how it should look. We do know that:

- A national self-advocacy resource should belong to and be controlled by a self-advocacy group with a good track record, not a university of some other part of the service system or a parent advocacy group.

Speaking for Ourselves in Philadelphia has a computer system for keeping track of people and resource materials.

- We want a clearinghouse because getting things done locally and at the state level takes so much energy that it's hard for us to find and share helpful information, materials, and other resources. We need a "Whole Earth Catalog" and people to keep it up to date (maybe NIDRR would fund a clearinghouse on empowerment).

- We want to widen and strengthen our network; person-to-person contact is the key.

Next Steps

❑ There are some things we can do without any additional money:

- We can find other ways to bring people together over the next year or so.

- We can send things to each other.

- We can call and ask each other for news, advice, and help.